

IMPLEMENTING HIV SELF-TESTING: A PRACTICE-BASED GUIDE





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INTRODUCTION AND BACKGROUND

HIV SELF-TESTING is a newer way to test for HIV and can be an integral component of a comprehensive testing strategy, complementing other methods such as point-of-care and laboratory testing. This approach is designed to empower individuals with the autonomy to test themselves at their convenience, thereby enhancing accessibility for first-time testers and encouraging regular testing. By diversifying testing options, HIV self-testing can address the unique needs and preferences of the communities most affected by HIV.

In this guide, we outline practice-based recommendations for implementing HIV self-testing, aiming to maximize its benefits and address potential challenges. The recommendations were informed by individuals representing community-based organizations (CBOs) that have played a leadership role in distributing HIV self-test kits in Canada. The goal of this guide is to provide healthcare providers and CBOs with guidance to enhance the effectiveness and reach of HIV self-test kit distribution, ultimately contributing to the broader goal of ending the HIV epidemic.

What is HIV self-testing?

HIV self-testing is a testing option that was licensed for use in Canada in November 2020. With a self-test, a person collects their own sample, conducts the test and interprets the result themselves. The self-test that is available in Canada uses a blood sample from a finger prick. It is a screening test, meaning that a reactive (positive) result needs to be confirmed by a laboratory HIV test.

"HIV self-tests are a screening tool, a starting point for a more holistic and comprehensive sexual health journey"

- Dialogue participant

HIV self-testing and reaching the undiagnosed

An estimated 11% of people living with HIV in Canada are unaware that they have HIV. This is particularly concerning for populations disproportionately impacted by HIV, including gay, bisexual and other men who have sex with men (gbMSM); people who use drugs; as well as Indigenous people and African, Caribbean and Black communities, including a disproportionate number of women from these communities. These groups face a disproportionate burden from broader social and structural factors, such as racism, homophobia and historical and ongoing colonialism, which can create barriers to accessing health services, including HIV testing. A multifaceted approach is required to address these factors and improve access to HIV testing among these communities.

"Decolonizing via increasing self-determination"

Dialogue participant

HIV self-testing is a low-barrier option that can increase access to testing by providing a private, convenient and accessible option for individuals; its flexibility can play an important role in broadening the reach of HIV testing efforts. HIV self-testing can be particularly effective in engaging communities that are underserved or less likely to participate in traditional testing options, such as individuals who experience stigma within the health system, people with concerns about confidentiality, those in rural and remote areas and those with busy lifestyles. HIV self-testing represents a significant opportunity to reach first-time testers. HIV self-testing can also be an important resource for repeat testers who are familiar with the testing process and seek more convenient access.

"This work addresses stigma, lots of folks testing for the first time"

- Dialogue participant

HIV self-testing is not just a method to increase testing rates; it serves as a gateway to a wider range of health and social services. HIV self-testing provides an opportunity to connect individuals with a variety of supports, ranging from sexual health education and prevention resources to mental health services and community supports. This holistic approach supports individuals to receive comprehensive care.

CBOs are well positioned to reach the groups that are most affected by HIV and distribute HIV self-test kits within these communities. CBOs have played an essential role in developing methods to increase awareness of HIV self-testing, distributing self-test kits and related resources and supporting linkage to HIV care, prevention and related support services.

"Gives people agency over their own bodies"

Dialogue participant



HOW THIS PRACTICE-BASED GUIDE WAS DEVELOPED

THIS PRACTICE-BASED guidance document was created to support the development and delivery of community-based HIV self-test kit distribution programs. The document draws on the guidance and expertise of selected CBOs, chosen by the Public Health Agency of Canada for their leadership in HIV self-test kit distribution, their regional representation and their service to the populations most affected by HIV. Representatives from these CBOs participated in a two-day in-person dialogue in Toronto, Ontario, on November 22 and 23, 2023, to inform the development of this guide (see Appendix 1 for a list of participating CBOs).

The dialogue consisted of facilitated discussions on predetermined topics and focused on effective strategies for HIV self-test kit distribution and lessons learned. Participants from CBOs shared their knowledge and expertise during small- and large-group discussions and provided insight into core areas of practice. Participants brought their knowledge of how to work with their unique communities to each discussion and provided valuable lessons learned based on their expertise. Notes were taken during the dialogue discussions, which were later organized around core topic areas. These were used by CATIE staff to develop the practice-based recommendations contained in this guide, which was then reviewed by four attendees of the dialogue. Quotations from dialogue participants are included throughout the guide.



THE STATUS-NEUTRAL APPROACH

A CONSISTENT THEME throughout the dialogue was the value of taking a status-neutral approach. A status-neutral approach promotes equality and inclusivity by treating all individuals, regardless of their HIV status, with dignity, respect and support. This approach acknowledges that everyone has the right to access information, services and resources related to HIV prevention, testing, treatment and care, regardless of whether they are living with HIV or not. By adopting a status-neutral perspective, service providers can reduce HIV stigma, which can encourage individuals to seek testing and care without fear of discrimination. Moreover, this approach emphasizes the importance of comprehensive support services that address the needs of both HIV-positive and HIV-negative individuals. This approach has been gaining popularity in recent years as an effective way to improve the health and well-being of people affected by HIV and to prevent HIV transmission, while also reducing HIV stigma.

"Creates opportunity for larger conversations"

Dialogue participant

WHAT YOU WILL FIND IN THIS PRACTICE-BASED GUIDE

This practice-based guide provides recommendations for community-based organizations to consider when developing and implementing approaches to distributing HIV self-test kits. The guide starts with recommendations on assessing your organization's readiness to distribute kits, establishing policies and procedures to support distribution, and providing staff training. It then provides recommendations on different approaches to distributing self-test kits (e.g., outreach, events, online). The guide ends with recommendations on building awareness and promoting self-test kits, preparing for pre- and post-test conversations and linking clients to health and support services (e.g., prevention services, HIV treatment services).



DECIDING WHETHER DISTRIBUTING HIV SELF-TEST KITS IS RIGHT FOR YOUR ORGANIZATION

BEFORE DECIDING to take on HIV self-test kit distribution, your organization's leaders should carefully consider whether this is a good fit for your organization. This involves assessing factors such as knowledge, resources and values within the organization to determine if your organization has the capacity and willingness to successfully adopt and integrate self-test kit distribution. Essentially, it's about making sure your organization is equipped and ready to tackle the challenges and opportunities that come with adding HIV self-test kit distribution to your programs and services.

Below are some practice-based recommendations for you to consider when deciding whether self-test kit distribution might be a good fit for your organization.

- 1. Determine if the distribution of HIV selftest kits aligns with your organizational goals and values.
- 2. Consider if your organization can reach communities disproportionately affected by HIV.
- 3. Consider how HIV self-testing fits within the landscape of HIV services in your community, including testing, prevention and treatment.
- Weigh the pros (e.g., increased accessibility) and cons (e.g., extensive staff training requirements) of HIV self-test kit distribution and base decisions on a comprehensive understanding of these factors.
- 5. Evaluate if your organization has or can acquire all the necessary resources (e.g., staff, space) to distribute HIV self-test kits.
- 6. Recognize the need to:
 - a. provide comprehensive training to staff to effectively distribute HIV self-test kits

- consult with staff to understand any concerns or anxiety related to implementation and delivery so they can be addressed during rollout
- c. conduct external consultations with stakeholders, including community consultations, to determine how best to distribute self-test kits
- d. determine the best ways to distribute HIV self-test kits in your community including considering how distribution can be integrated into existing programs and services
- e. increase awareness of the self-test kits in the community
- f. ensure your organization's readiness to address logistical considerations such as procuring and storing the HIV self-test kits to facilitate smooth implementation
- g. develop policies and procedures to guide the distribution of self-test kits
- h. develop a clear linkage to care pathway for both reactive results (e.g., confirmatory testing) and non-reactive results (e.g., HIV prevention)



MEANINGFUL INVOLVEMENT OF PEOPLE AFFECTED BY HIV

WHEN YOUR ORGANIZATION decides to start HIV self-test kit distribution, it's important to prioritize the meaningful involvement of the communities disproportionately affected by HIV in the development and delivery of your approach. This includes people living with HIV; gay, bisexual and queer+ guys; people who use drugs; as well as Indigenous people and African, Caribbean and Black communities, including a disproportionate number of women from these communities. Work should be grounded in the principles of Meaningful Engagement of People Living with HIV (MEPA), Greater Involvement of People Living with HIV (GIPA) and "nothing about us without us." Committing to these principles throughout the community consultation process, program development and program delivery demonstrates a dedication to inclusivity and empowerment. Recognizing that meaningful engagement is vital for effective decision-making and action, these processes require time and careful attention to the unique needs of the populations you aim to engage, including cultural competency, community leadership and a commitment to collaboration.

"Include lived experience in planning and leadership"

- Dialogue participant

"Why are you doing it? Who are you doing it for? And how have you meaningfully involved those community members?"

- Dialogue participant

Below are some practice-based recommendations for you to consider when determining how to meaningfully engage the communities that you serve in community consultations and program delivery.

Practice-based recommendations:

Community consultations

- Conduct community consultations at every stage of decision-making and planning to ensure sustainable, accessible, inclusive and communitydriven approaches to HIV self-test kit distribution.
- 2. Consult documents with relevant guidance before you begin community consultations, such as the following:
- <u>Truth and Reconciliation Commission of</u> <u>Canada: Calls to Action</u> when working with Indigenous communities
- GIPA and MEPA principles as outlined in the <u>Paris Declaration+20</u> and <u>UNAIDS</u> <u>GIPA Policy Brief</u> when working with people living with HIV
- <u>Peer Engagement Principles and Best</u>
 <u>Practices</u> and <u>Hear Us, See Us, Respect</u>
 <u>Us guidance</u> when working with people who use drugs

- 3. Create an engagement strategy to effectively reach the communities that you serve (e.g., people living with HIV, people who use drugs, gay men, Indigenous people) for consultation. To minimize the burden of consultation on a community, consider opportunities to leverage existing advisory committees or partnerships.
- 4. Leverage the knowledge and expertise from the communities that you serve by collaborating with them to brainstorm and develop strategies to improve community engagement. For example, when working with Indigenous communities, ensure Indigenous collaborators design engagement and consultation processes that reflect appropriate community practices and approaches to consultation. Focus on decolonizing consultation approaches to ensure they are relevant and relatable to community members.
- 5. Ensure that community consultations foster trust, accountability and transparency, to lay the foundation for collaborative and impactful initiatives.
- 6. Ensure that community consultations seek to dismantle power imbalances and promote equity.

Program delivery

- Incorporate individuals from the communities you serve into planning and staff roles, including leadership positions, to harness their valuable insights and perspectives, thereby guiding program design and implementation.
- 2. Empower staff from the communities that you serve to participate in decision-making processes and service delivery.

- Ensure equitable compensation for staff from the community by providing a fair and sustainable living wage. Longer term contracts should be considered to allow staff the opportunity to develop their skills and foster relationships within the community.
- 4. Foster trust and comfort among the communities you serve by hiring staff from the same communities to provide support and guidance during the testing process.
- 5. Train community staff members to promote and implement the distribution of self-testing kits, equipping them with the necessary skills to foster open discussion, and provide accurate information about the self-test.
- 6. Provide community staff members with a suite of consistent and ongoing supervision and peer-to-peer supports.
- 7. Hire individuals living with HIV.

 Storytelling, education and support delivered by people living with HIV can destigmatize testing, emphasize that individuals can live well with HIV and highlight the importance of treatment in empowering individuals to take control of their health.
- 8. Collaborate with community leaders, including Elders, from outside of your organization to ensure staff from the community are supported and that programs and delivery methods are designed and delivered in a manner that honours their culture, traditional practices and values.



POLICIES AND PROCEDURES

POLICIES AND PROCEDURES help organizations ensure that they are offering services consistently and in adherence with legal and ethical standards. Clear policies and procedures will provide guidance to staff on how to safeguard confidentiality and decide where and how to make referrals. This allows organizations to provide responsive and client-centred care while upholding quality standards that ensure the highest level of care for clients.

The following best-practice recommendations outline approaches to consider when developing, implementing and refining policies and procedures to support HIV self-test kit distribution.

- Establish detailed protocols for HIV self-testing to ensure consistency of service delivery and adherence to ethical standards.
- Create internal structures and protocols to guide responses in the event of a reactive test result, including clear pathways for follow-up care, support and referral.
- 3. Create internal structures and protocols to guide responses to non-reactive test results including clear pathways to HIV prevention services, support and referral.
- Involve community staff members in the design of policies and procedures to leverage their expertise and perspectives, promoting ownership and buy-in.
- 5. Develop a new or adapt an existing confidentiality policy on self-testing. Include clear accountability outcomes related to breach of confidentiality.

- 6. Develop a new or adapt an existing policy on boundaries between staff and clients with respect to self-testing. Include clear accountability outcomes related to breach of boundaries.
- 7. Establish a procedure for ordering and restocking self-test kits to maintain sufficient inventory.
- 8. With the guidance of community members, ground policies and procedures in community and culturally sensitive approaches to service delivery. For example, tailor policies and procedures to resonate with communities.
- Regularly review and update policies and procedures in response to changing needs, emerging evidence and feedback from staff and clients, to maintain relevance and effectiveness over time.



KNOWLEDGE ABOUT SELF-TESTING AMONG COMMUNITY ORGANIZATIONS AND PUBLIC HEALTH AUTHORITIES

ORGANIZATIONS SHOULD WORK to raise awareness of HIV self-testing and build support among stakeholders within their community. By prioritizing relationship building with local public health authorities and community-based organizations, organizations can establish trust and support for self-test kit distribution within the community. Proactive engagement can also help to strengthen self-test kit distribution and sustain the work by ensuring buy-in of local governments, local leaders and organizations with similar mandates.

"Secure community partner buy-in before starting"

Dialogue participant

The following best-practice recommendations outline strategies to consider when working to increase the knowledge of HIV self-testing among community organizations and local public health authorities.

- 1. Inform local public health authorities about your HIV self-test kit distribution program, providing details on the accuracy of the test, Health Canada approval and the need for confirmatory testing following a reactive result. This will help them prepare for a potential increase in confirmatory HIV testing and will alert them to the need to link people to care and conduct contact tracing.
- Increase awareness of your organization's self-test kit distribution program within community-based organizations in your area that are serving similar communities.
- 3. If your organization is planning to distribute HIV self-test kits in communities outside your own, ensure local buy-in and support.
- 4. Consider working with local, provincial or territorial government authorities and Indigenous governing bodies to secure their support.



EDUCATION AND TRAINING

ORGANIZATIONS NEED to develop staff training to support the distribution of HIV self-test kits. Training staff on self-testing is essential to ensuring that messaging is consistent, that the information provided to clients is of high quality and that staff are prepared to field questions from clients. Preparing staff with the knowledge they need to have informed conversations is crucial, as is preparing them with the skills to deliver this information to clients in a sensitive and respectful way. Education and training should prepare staff to provide culturally safe approaches (e.g., trainings tailored to resonate with communities) that allow them to support diverse communities and work in different contexts (e.g., outreach, in-office, online).

"Treat folks as an individual not another cookie cutter engagement. Meet folks where they are at with facts and myth busting"

Dialogue participant

The following best-practice recommendations outline strategies to consider when developing and implementing effective staff training approaches related to HIV self-testing services.

- 1. Aim to train staff members who may engage with self-testing to ensure consistent and high-quality service delivery.
- When designing staff training, reflect on concerns identified during staff consultations and tailor the training to address these issues (e.g., anxieties related to self-testing).
- 3. When developing training, cover a diverse range of topics so that staff have the information and skills they need to effectively distribute HIV selftest kits. Training should include the following components:
 - a. Familiarize staff with standardized policies and procedures for HIV self-test kit distribution.
 - b. Provide comprehensive education on HIV basics, including HIV

- transmission, prevention (e.g., PrEP), testing and treatment information.
- c. Provide information on HIV self-testing (e.g., approval of the HIV self-test, the accuracy of the self-test, the need for confirmatory testing following a reactive result, the window period of the test, self-test storage requirements).
- d. Equip staff with the information they need to provide pre-test information so that they can empower clients with accurate information and address any concerns or misconceptions they may have. Equip staff with the information and skills they need to provide effective post-test information including providing support, addressing emotional reactions and facilitating appropriate follow-up.

- e. Discuss the potential legal implications of HIV non-disclosure in your area.
- f. Provide training on practical skills such as active listening, test facilitation and how to support people who are anxious about taking the test. It can be helpful to facilitate opportunities for staff to engage in role-playing exercises to practise these skills.
- g. Emphasize the importance of facilitating immediate linkage to prevention, treatment or support services on the basis of an individual's specific needs and preferences, regardless of their HIV status.
- h. Discuss the need to maintain professional boundaries and client confidentiality to uphold trust and ethical standards. Offer strategies for managing challenging situations where boundary or confidentiality issues may arise.
- i. Discuss the importance of addressing conflicts of interest. This includes offering strategies for effectively managing conflicts of interest while prioritizing the well-being and rights of the client.
- 4. Use culturally safe and contextually appropriate training methodologies, materials and information to ensure effective learning experiences. Tailor training to resonate with participants from diverse cultural backgrounds and contexts. Incorporate locally relevant knowledge and skills that acknowledge the unique needs and perspectives of the community being served.

- 5. Support staff in understanding cultural humility and providing culturally safe environments. Encourage continuous self-reflection and lifelong learning about diverse cultural perspectives. By prioritizing humility, empathy and respect, staff can build trusting relationships with clients from various backgrounds, promoting inclusivity and reducing barriers to care.
- 6. Provide hands-on demonstrations (e.g., staff do a test), practical walkthroughs and/or scenarios to reinforce staff learning and ensure that staff are comfortable explaining how to use self-test kits and conducting preand post-test conversations.
- Foster a supportive and non-judgmental environment for staff to address stigma and enhance their confidence in delivering self-testing services effectively.
- 8. Use resources (e.g., online and print) from external organizations to support the training you provide and to stay updated on best practices in self-testing implementation.
- Encourage a culture of continuous learning and openness to new information among staff to ensure that everyone in your organization stays informed about HIV and evolving best practices in testing and support services.
- 10. Implement ongoing training initiatives to support frontline staff in delivering responsive and flexible HIV self-testing programming.



SELF-TEST KIT DISTRIBUTION

THE GOAL OF HIV self-test kit distribution should be to enhance the accessibility of self-testing by implementing distribution methods informed by your community and that are practical for your organization. The distribution of HIV self-test kits can be integrated into existing services, or new ways of distributing self-test kits can be developed. Kit distribution methods should be responsive to the needs of communities and consider the unique barriers that exist. Strategies should aim to be as low-barrier as possible, bringing tests to where people are and encouraging approaches such as secondary distribution to extend reach. There is no one-size-fits-all approach to self-test kit distribution, and organizations may consider using multiple approaches to reach different community members at different times. Regardless of the approach, self-test kit distribution is an opportunity to engage with clients, assess their health and social support wants and needs, normalize testing and help them to connect with services.

"Relationships built through distributing self-test kits"

Dialogue participant

The following best-practice recommendations outline strategies to consider when developing approaches to distribute HIV self-test kits. Specific practice-based recommendations for different distribution methods follow.

- Consider the various ways that self-test kits could be distributed. Ensure that the distribution method(s) your organization chooses to implement meet(s) the needs of your community and is (are) within your organization's capacity.
- 2. Taking into consideration your organizational capacity, consider using multiple distribution methods both within and outside of your organization.
- 3. Integrate self-testing kit distribution into existing programs and services (e.g., workshops, naloxone training, needle and condom distribution)

- through careful planning and coordination to maximize efficiency and minimize disruption to ongoing activities.
- Make self-test kits visible and easily accessible in-office (e.g., reception desk), allowing individuals to pick them up during appointments or visits.
- 5. Consider ways to distribute self-test kits discreetly (e.g., unbranded gift bags, washrooms).
- 6. Make your distribution strategies as low-barrier as possible for the communities that you are aiming to reach.

- Make self-test kits available in more locations and bring tests to where people are both within and outside of your organization (e.g., drop-in programs that distribute food, community-based shelters).
- 8. Encourage and support people to take more tests than they need to distribute to friends, family or peers (i.e., secondary distribution). This reaches people who are hesitant to access healthcare and social services themselves.
- Consider exploring innovative distribution methods, such as vending machines, to increase the accessibility and visibility of self-test kits.
- 10. Consider whether your organization will allow people to test on-site. If you allow on-site testing, provide private, comfortable spaces for people to do the test, with optional support from trained staff. Establish clear policies and boundaries for these testing procedures.
- 11. Consider providing real-time support (e.g., phone or text support) to people who are testing off-site. This support should be offered in a confidential and accessible manner.

- 12. Consider the feasibility of offering HIV confirmatory testing through each distribution mechanism your organization uses. This may be particularly relevant in rural communities where access to confirmatory testing is limited.
- 13. Consider distributing HIV self-test kits alongside other resources that promote health and well-being (e.g., condoms, lubricants, water bottles, hygiene kits and harm reduction supplies). Offering a variety of items gives people a discreet way to access kits and gives you an opportunity to provide more resources to clients.
- 14. Consider including informative materials in a package along with the self-test kit. This can include a pamphlet about how the self-test works, local information about where to go for confirmatory testing and information on HIV prevention.
- Develop and provide inclusive and affirming spaces for open discussions around HIV self-testing.
- 16. Ensure distribution methods are designed with insights from community leaders, including Elders, to ensure delivery methods honour and reflect community values and culture.



DISTRIBUTION IN DROP-IN SETTINGS

DROP-IN PROGRAMS and services are available without an appointment and take place during consistent hours to provide clients with a dependable and flexible way to access services, including HIV self-test kits. Organizations can consider integrating HIV self-test kit distribution into existing drop-in services or develop new drop-in services specifically for the distribution of self-test kits. Drop-in programs can provide a convenient way for clients to pick up tests in a familiar setting. Drop-ins also provide an opportunity for clients to connect with staff immediately and can help to facilitate referrals to other services. Drop-ins offer an excellent opportunity to provide self-test kits to those already familiar with your organization.

"Alleviates some pressure from traditional testing streams"

- Dialogue participant

The following best-practice recommendations outline strategies to consider when developing or integrating approaches to distributing self-test kits in drop-in settings.

- Consider integrating self-test kit distribution into existing drop-in services or developing new drop-in services related to self-testing.
- 2. Always have staff who are trained in self-testing available during drop-in times so that individuals can receive support and assistance.
- 3. Create a relaxed and welcoming environment that can help mitigate potential barriers to accessing testing services.
- Consider designating specific drop-in times for first-time testers tailored to address their specific needs and barriers.



DISTRIBUTION THROUGH OUTREACH

OUTREACH PROGRAMS increase access by bringing services to people in the community with a flexible and proactive approach that meets them where they are. Organizations can consider integrating HIV self-test kit distribution into existing outreach services or develop outreach services that are specifically dedicated to the distribution of self-test kits. Bringing self-test kits out to communities with other services (e.g., distribution of sexual health and harm reduction supplies) can help to normalize and destigmatize HIV testing and to act as a conversation starter and a way to engage clients in discussions about other supports that they may want. However, outreach can be challenging if organizations are not well connected to the community and are unaware of locations that could be good places to meet community members. Outreach is also resource intensive as it requires travelling and taking the time to engage with people on a variety of topics.

"Bringing the test to people instead of bringing people to the test"

- Dialogue participant

The following best-practice recommendations outline strategies to consider when developing or integrating approaches to distributing HIV self-test kits through outreach.

- 1. Consider integrating self-test kit distribution into existing outreach services (e.g., harm reduction and safer sex supply distribution) or developing new HIV-self testing outreach services. Consider having outreach workers take self-test kits with them whenever they are out in the community.
- 2. Consider conducting street-based outreach initiatives in locations where the communities that you are trying to reach gather (e.g., encampments, parks).
- 3. Consider distributing self-test kits in trusted community spaces (e.g., bathhouses, bars, up a self-test kit dispenser in these locations.
- 4. Consider using mobile outreach vans, particularly in rural and underserved areas where

- healthcare services may be limited or where people may face other barriers to accessing services. This can provide convenient access to self-test kits alongside other services and supplies (e.g., testing programs, sexual health or harm reduction supplies).
- 5. Consider establishing alliances with religious leaders to promote HIV testing within religious spaces, recognizing the importance of respecting cultural and religious beliefs and working collaboratively to address concerns and build trust through open dialogue and understanding.
- shelters and barber shops). Consider setting 6. If partnering with Indigenous organizations on outreach initiatives, engage with respect and cultural humility. Use approaches that will resonate with the communities that you serve (e.g., land-based approaches to outreach).



ONLINE DISTRIBUTION

ONLINE APPROACHES allow clients to access services (e.g., ordering a self-test kit) from anywhere with an Internet connection and have a self-test kit sent to them. By using online distribution, organizations can integrate HIV self-testing into existing online services or develop new online services to increase the accessibility of self-test kits. Online self-test kit distribution has the potential to increase access to HIV testing in locations where services are limited (e.g., rural and remote communities) and for populations that do not feel comfortable accessing health services because of stigma or other barriers. While online self-test kit distribution can increase accessibility, access to online services requires access to the Internet and a device (e.g., smartphone, laptop) and access to an address, which some people may not have. Another issue with online distribution is that clients may access self-test kits in areas with limited confirmatory testing and support services, resulting in issues with linkage to care following a test.

"Offers confidentiality for people who live in small communities who may know staff at the clinics/labs"

- Dialogue participant

"Reduces awkward conversations with medical staff about risk and exposure"

Dialogue participant

The following best-practice recommendations outline strategies to consider when developing or integrating approaches to distributing HIV self-test kits online.

- Consider integrating self-test kits into existing online services (e.g., mailouts, online outreach) or developing new online services.
- 2. Consider developing user-friendly online order forms that allow people to order self-tests for delivery (e.g., mail, bike) or pickup from your organization.
- 3. If providing an online ordering system, implement address validation tools and automated messaging systems to ensure accurate information input and timely delivery of self-test kits.
- 4. Prioritize data security and privacy considerations when implementing online distribution systems. Ensure that sensitive information is protected and that users feel confident in their privacy when accessing self-test kits online.
- Consider how to provide information and support (i.e., linkage to care) to people who receive self-test kits through online services.



DISTRIBUTION AT EVENTS

EVENTS TAKE PLACE within the community and can bring services to large groups of people at once. Organizations can integrate HIV self-testing into their own events or offer it at events organized by other organizations. This can improve accessibility and inclusivity for diverse populations and provide a way to normalize HIV testing. Event distribution can bring self-test kits directly to the populations most affected by HIV and be a way to reach new audiences. The benefits of organizing your own events include the ability to specifically market to the audience you would like to reach and the ability to set the parameters (e.g., place, time) for the event. Distributing self-test kits through events organized by others can enable your organization to reach different populations. A potential challenge with events is that the ability to have detailed conversations with participants may be limited because of time and space constraints.

"Decentralize access to HIV testing"

Dialogue participant

The following best-practice recommendations outline strategies to consider when developing or integrating approaches to distributing self-test kits at events.

- Consider facilitating the distribution of self-test kits at events hosted by other organizations that reach the communities most affected by HIV (e.g., Pride events).
- 2. Educate event organizers to increase their knowledge of self-testing and gain buy-in.
- 3. Consider organizing events for the communities that you serve, either independently or in collaboration with other organizations.
- 4. Led by, or working in partnership with, Indigenous organizations, consider distributing self-test kits through Indigenous events. This may be an effective way to create a culturally relevant approach to increasing access
- to HIV testing. By embedding testing initiatives within traditional or other community gatherings that utilize land-based approaches (e.g., use of the medicine wheel, medicine bundles, ceremony), organizations can foster trust, respect cultural protocols and reach individuals who may not otherwise access testing services. This approach respects Indigenous ways of knowing and being and acknowledges the importance of community connection in health promotion.
- 5. At events, make the self-test kit visible and provide demonstrations if feasible.
- 6. Use attention grabbers, such as games, conversation starters and peer engagement, to generate interest in the self-test kit.



AWARENESS AND PROMOTION

ORGANIZATIONS NEED to raise awareness about HIV self-testing and promote self-testing among the communities that they serve. As you develop your awareness and promotion efforts, consider how to reach the populations that are most affected by HIV and recognize that without first increasing awareness of the HIV self-test kits, uptake of the self-test kits will be limited. Different communities will have different information needs and concerns (e.g., confidentiality, accuracy) and may require different promotional approaches to effectively engage. There is no one-size-fits-all approach to promoting HIV self-testing and building awareness; rather, your organization's efforts should consider the unique needs of each community that you serve.

"Use expired kits to do a demo"

- Dialogue participant

Below are some practice-based recommendations for you to consider when determining how to promote and increase awareness of HIV self-test kits within the communities that you serve.

- Consider developing social media and other marketing campaigns to educate the communities most affected by HIV about the availability and benefits of HIV self-testing.
- 2. Consider implementing targeted online advertising on various platforms (e.g., social media, dating apps).
- Consider distributing self-testing promotional materials through existing channels (e.g., cards in condom packs, posters in waiting rooms).
- 4. Address concerns regarding the accuracy and confidentiality of HIV self-testing through messaging that is tailored to specific communities and needs.
- 5. Ensure that communities are represented in promotional materials.

- To capture audience attention, use engaging and interactive content formats, such as videos and infographics.
- 7. Consider what types of promotions to run on the basis of your distribution methods. For example, when distributing at events, promote self-test kits through social media before the event and ask organizers to help spread the word that self-tests will be available.
- 8. Consider promoting the self-test kit through live demonstrations that make the test more familiar and less intimidating and that showcase its simplicity.
- 9. Promote self-test kits to people seeking other services at your organization.



PRE- AND POST-TEST CONVERSATIONS

PRE- AND POST-TEST CONVERSATIONS and information can provide support for individuals who are receiving HIV self-test kits, addressing stigma, providing accurate and accessible information and promoting linkage to care and support services. This may be done in person or through other means (e.g., pamphlets attached to the kit, online). These conversations can be an important part of normalizing HIV testing and should be approached with sensitivity, empathy and sex positivity, while recognizing an individual's autonomy.

"Being willing to sit with and listen to folks, giving them time and space to feel their emotions"

Dialogue participant

"Always remember what your first test was like and what a positive result felt like" – Dialogue participant

Below are some practice-based recommendations for you to consider when determining how to have pre- and post-test conversations with clients, as well as considerations around what to do when conversations may not be possible or desired by the individual taking the test.

- 1. Recognize that some people may want to engage in detailed conversations about self-testing while others will want to simply take a self-test kit. Respect each person's autonomy, tailor the information that you provide to their needs and preferences, and plan for other ways of sharing information if needed.
- Recognize that not every situation is practical for detailed pre- and/or post-test conversations, and plan alternative methods for sharing information. Consider directing individuals to online resources or providing print materials like postcards, pamphlets or stickers when conversations are not possible or desired.
- Consider including key messages and contact information for your organization with the self-test kits so people know who to follow up with if they have questions or concerns.
- 4. When feasible and desired, provide pre-test information covering educational topics relevant to the person and the situation (e.g., HIV basics, how to conduct a self-test and interpret the results).
- 5. When feasible and desired, provide post-test information covering educational topics relevant to the person and the situation (e.g., prevention of sexually transmitted infections, referral pathways for both HIV prevention and treatment services, the need for confirmatory testing, legal issues).

- Inform individuals that support is available to them regardless of their test result and assure them that referrals to care and other services are available.
- 7. Create a safe and respectful environment to talk about sex and drug use and challenge HIV-related stigma and inaccurate information.
- 8. If you have expired self-test kits, consider using them to demonstrate how to use the test during your conversations. This can help to reduce anxiety about taking the test or confusion about how the test works.
- 9. Consider strategies to address individuals' concerns about receiving a positive result by helping them prepare for the possible outcomes and understand what the next steps might be.
- 10. If safety concerns are raised by an individual (e.g., if a person expresses concern that their partner might react negatively), provide support and appropriate referrals or alternative testing options.
- Continuously assess and adapt conversations and information-sharing approaches on the basis of feedback from clients.
- 12. Consider providing staff with key messages or scripts to facilitate pre- and post-test conversations.

- 13. Provide a supportive environment for individuals with invalid results and be prepared to provide reassurance and guidance on repeat testing. Let individuals know that they can reach out to your organization if they have invalid results for more tests or support.
- 14. Provide a supportive environment for individuals with reactive results, allowing them time to process the information and express their feelings and concerns. Provide silence and time if needed. When the person is ready, discuss next steps including confirmatory testing and linkage to care.
- 15. Provide a supportive environment for individuals with a non-reactive result and allow them to ask questions and express feelings and concerns. Be prepared to provide referrals to prevention services or other needed support services.
- 16. Respect the lead of clients in determining the pace and depth of discussions, ensuring that they feel empowered and in control of their care decisions.
- 17. Ensure that all staff have access to support services to address emotionally difficult situations with clients, including referrals to services at other organizations when appropriate or desired.



TIPS AND TRICKS

THERE ARE SOME tips and tricks that can be communicated to people who are self-testing that will help them to conduct the test. This can help clients to feel more at ease completing the test and can result in fewer invalid or inaccurate results overall. It is also important to understand the full INSTI HIV Self Test Instructions For Use.

"Take more than one kit in case you mess up the first one"

Dialogue participant

Below are some practice-based recommendations for you to consider related to providing tips and tricks that could help your clients to complete an HIV self-test effectively and help your organization to assist in the distribution of self-test kits.

- 1. Direct people to the instructions inside the kit or an online video for information about how to do the test.
- Consider providing tips and tricks to help people take the test correctly. This may be particularly helpful for people who are using a self-test for the first time.
 - a. Provide tips on how to make it easier to draw a drop of blood (e.g., warming their hands before taking the test and rubbing from their palm out to their fingertip before pricking their finger).
 - b. Explain that a full drop of blood needs to fall into the bottle. Scraping some blood from their finger into the bottle may result in the blood sample being too small and the test result being invalid.
 - c. Advise people that the contents of the bottle should be dark red after they add their blood sample. They should add a second drop of blood if necessary.

- d. Encourage people not to test in a hot and humid environment, as this increases the chance of a false-positive result.
- e. Tell people that the tests should be stored at room temperature.
- f. Advise people to avoid using hand sanitizer, which may produce an invalid result. Instead, people should wash and dry their hands before taking the test, or they can use an alcohol swab.
- g. Instruct people to open the bandage before they prick their finger, so that it is ready to put on quickly after they draw the drop of blood.
- 3. Have additional supplies on hand (e.g., extra lancets, alcohol swabs and bandages) for people to take.
- 4. Encourage people to take multiple selftest kits in case they get an invalid result and need to do the test again.
- Consider creating a card to hand out with tests that contains tips and tricks (e.g., using multiple drops of blood, warming hands).



LINKAGE TO CARE: ESTABLISHING PATHWAYS TO PREVENTION SERVICES, CONFIRMATORY TESTING, HIV CARE AND OTHER SERVICES

CONNECTING PEOPLE who self-test to a wide variety of health and social services (i.e., prevention services, confirmatory testing, HIV treatment) is an important part of HIV self-test kit distribution and should emphasize collaboration and client-centred care. Pathways to services should be established before your organization begins to distribute HIV self-test kits. Different pathways are appropriate for different people, so it is important to have multiple pathways to similar services, if possible, as well as pathways to the array of services that a client may need (e.g., pre-exposure prophylaxis prescribing, confirmatory testing, housing supports). Organizations can facilitate linkage to care by providing comprehensive information about the possible pathways to care and respecting individual preferences and choices. Information on pathways can be shared in pre- and post-test conversations or through materials in a self-test kit. Staff should be available to support people to link to needed services when they are ready and be prepared to provide options.

"Be informed about different pathways to care and understand that not everyone will want to take the same path"

Dialogue participant

"Use it as an opportunity to assess other needs and promote other services"

Dialogue participant

The following best-practice recommendations outline strategies to consider when establishing pathways to care and linking clients to prevention services, confirmatory testing, HIV care and other health and social services.

- Establish a list of referral pathways
 for prevention services, confirmatory
 testing, linkage to care and treatment
 and other health and social services.
 You can do this by working with local
 healthcare providers, community organizations and public health authorities,
 as well as through recommendations
 from partner organizations and word of
 mouth from community members.
- 2. Consider developing service agreements to support care and referrals.
- 3. Ensure that everyone, regardless of their test results, receives equitable access to relevant care including prevention, confirmatory testing, treatment supports and other health and social services.

- 4. Provide accessible resources, such as informational cards, QR codes, pamphlets and a dedicated webpage, to empower individuals with information on care pathways.
- 5. Facilitate timely linkage to confirmatory testing for people with a reactive test result. Consider different pathways to encourage confirmatory testing including on-site confirmatory testing, mobile testing clinics, and partnerships with public health, laboratories and/or physicians.
- Consider offering warm referrals, appointment accompaniment and peer support, to help individuals access the services they need.
- Consider offering transportation assistance to individuals who need to access confirmatory testing, healthcare appointments or other services.

- 8. Consider advocating for needed services such as expanded access to HIV testing and treatment services (e.g., expanded clinic hours and flexible scheduling to accommodate diverse needs). As appropriate, work with stakeholders to address barriers and improve healthcare delivery.
- 9. Prioritize client-centred care by empowering individuals to make informed decisions about their healthcare journey, including the timing of treatment initiation. Ensure that individuals are aware of their rights and options regarding treatment.
- 10. Consider how to support or refer individuals to comprehensive support services beyond care and prevention of sexually transmitted and bloodborne infections, including assistance with housing, legal support, food security, mental health services and income support.



CONCLUSION

HIV SELF-TESTING can be an integral component of a comprehensive testing strategy, complementing other methods such as point-of-care and laboratory testing. This practice-based guide provides recommendations to help community organizations support the uptake and integration of HIV self-testing into their services. By considering these practice-based recommendations, organizations can maximize the potential of HIV self-testing as a tool to reach undiagnosed individuals.



Community-based organizations that participated in the National HIV Self-testing Dialogue

2-Spirited People of the 1st Nations, Toronto, Ontario

AIDS Committee of Cambridge, Kitchener, Waterloo and Area, Waterloo, Ontario

AIDS Programs South Saskatchewan, Regina, Saskatchewan

Asian Community AIDS Services, Toronto, Ontario

Black Coalition for AIDS Prevention, Toronto, Ontario

Community-Based Research Centre, Vancouver, British Columbia

GetaKit, Ottawa, Ontario

GAP-VIES, Montreal, Quebec

Halifax Sexual Health Centre, Halifax, Nova Scotia

Maggie's Toronto Sex Workers Action Project, Toronto, Ontario

Manitoba Harm Reduction Network, Winnipeg, Manitoba

MAX Ottawa, Ottawa, Ontario

MIELS-Québec, Quebec City, Quebec

Nine Circles Community Health Centre, Winnipeg, Manitoba

PEERS Alliance, Charlottetown, Prince Edward Island

RÉZO, Montreal, Quebec

REACH Nexus I'm Ready, Toronto, Ontario

Ribbon Rouge Foundation, Edmonton, Alberta

SafeLink Alberta, Calgary and Medicine Hat, Alberta

Sandy Beach Kimamow Atoskanow Foundation, Onoway, Alberta

Turning Point Society, Red Deer, Alberta

Women's Health in Women's Hands Community Health Centre, Toronto, Ontario

Observers

CATIE

Public Health Agency of Canada



List of CATIE resources

HIV self-testing

HIV self-testing – fact sheet

CATIE statement on the HIV self-test as a highly effective tool for increasing uptake of testing in Canada

HIV self-testing – information for clients

HIV basics

HIV Basics - online course

The HIV Handbook - online resource

HIV Transmission – fact sheet

HIV Basics - brochure for clients

HIV testing

HIV and Hepatitis C Testing - online course

The HIV testing process – fact sheet

HIV testing technologies - fact sheet

I Know My HIV Status: Facts About HIV Testing – brochure for clients

HIV Testing: Everything you need to know - booklet for clients

HIV prevention

HIV prevention – online course

HIV treatment and an undetectable viral load to prevent HIV transmission - fact sheet

Pre-exposure prophylaxis (PrEP) - fact sheet

Post-exposure prophylaxis (PEP) - fact sheet

Condoms for the prevention of HIV transmission – fact sheet

The Power of Undetectable: What you need to know about HIV treatment as prevention – booklet for clients

PrEP to Prevent HIV: Your Questions Answered – brochure for clients

PEP: Preventing HIV after a potential exposure – booklet for clients

HIV treatment

HIV treatment - online course

HIV treatment - fact sheet

Your Guide to HIV Treatment - booklet for clients



Acknowledgments

We are very grateful to the representatives from the 22 community-based organizations (see Appendix 1 for a list of participating CBOs) who came together to share their experiences and expertise, and without whom this guide would not be possible. We are also grateful to our external reviewers Scott Alan, Denise Lambert, Michelle Muchetu and Shiny Mary Varghese; our designer Rick Smith; and our copy editor Jennifer Thomas.



National HIV Self-testing Dialogue

November 22 and 23, 2023 | Hilton Toronto Airport Hotel & Suites Dundas room

What to Expect Movement around the room Talking with peers at tables Talking with peers at tables Breakout groups based on topic/focus It is tening to presenters Breakout groups based on topic/focus Live survey using a device Virting and independent thought

The dialogue will take place in both French and English. To encourage participants to speak and feel understood in the language of their choice, we strongly encourage participants who are not fluent in both languages to obtain simultaneous interpretation headsets before the sessions begin each day and prepare to use them as needed.

- DAY ONE -				
Timing	Session Topic	What to Expect		
8:00 am-9:00 am	Registration & Breakfast Join us any time after 8 am			
9:00 am–10:00 am	 Kick Off Elder Naulaq to open Christie Johnston, CATIE (5 minutes) Tagenine Alladin, Public Health Agency of Canada (5 minutes) 	<u>&</u> 4) Ø		
10:00 am-10:15 am	Break			
10:15 am-11:45 am	Situating HIV Self-testing Within the Broader Testing Landscape	# 9 C		
11:45 am-12:45 pm	Lunch Break			
12:45 pm-1:45 pm	Organizational Readiness			
1:45 pm-2:30 pm	Community Readiness	* 4 *		
2:30 pm-2:45 pm	Break			
2:45 pm-4:35 pm	Promotion and Distribution Methods	# ☆ № □		
4:35 pm-5:00 pm	Closing			
5:00 pm – 7:00 pm	Reception at Hilton Toronto Airport Hotel & Suites	◄		

- DAY TWO -

Timing	Session Topic	What to Expect
8:00 am-9:00 am	Breakfast Join us any time after 8am	
9:00 am-9:30 am	Kick Off Semhar Zerat, Public Health Agency of Canada (5 minutes)	
9:30 am-11:30 am	Conversations Surrounding Self-tests: Supports, Information Requirements, and Pre and Post-Test Conversations	
	Break will take place mid-session, around 10 am	
11:30 am-12:30 pm	Lunch Break	
12:30 pm-2:15 pm	Pathways to Care: Confirmatory Testing, Prevention, and Support Services	
2:15 pm-2:30 pm	Break	
2:30 pm-3:30 pm	Practice-based Guide Development: Discussion	
3:30 pm-4:00 pm	Closing	